

DOCUMENT RESUME

ED 157 328

EC 111 813

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TITLE The Future of the Handicapped Person and His Community.
PUB DATE Jun 78
NOTE 12p.; Paper presented at the World Congress on Future Special Education (First, Stirling, Scotland, June 25 - July 1, 1978)
EDRS PRICE MF-\$0.83 HC-\$1.67 Plus Postage.
DESCRIPTORS Community Programs; Cost Effectiveness; *Futures (of Society); *Handicapped; Home Instruction; Intervention; *Mentally Handicapped; Normalization (Handicapped); Prevention

ABSTRACT

The author predicts major innovations in the future of the handicapped person in his community. Future trends are reported for the following eight areas: research and prevention efforts on decreasing the incidence of the more severe handicapping conditions, impact of the ideology of normalization, parents of the retarded, self advocacy for handicapped citizens, consumer advocate capabilities for catalyzing and monitoring community services for the mentally retarded and other developmentally disabled, home training for severely handicapped citizens, curative approaches to the mentally retarded, and cost-benefit considerations in community service provision. (Author/SBH)

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AUG 25 1978

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THE FUTURE OF THE HANDICAPPED PERSON

AND HIS COMMUNITY

Presented at the First World Congress of the Council for Exceptional Children, Stirling, Scotland, June, 1978

Introduction

It is at all times rather risky to attempt to predict the future. In this area of the future of the handicapped person in his community, it is my impression that eight current trends -- each in their early phase of growth -- will become the major thrusts of the future. Each of these future oriented trends will be briefly reviewed.

Current-Future Trends

The future of the handicapped person in his community will encompass, in my opinion, the results of major innovations in the following eight areas:

A. The dramatic impact of research and prevention efforts on decreasing the incidence of the more severe levels of handicapping conditions. We are already noting enhanced prevention of mental retardation from (1) regionalized comprehensive pre-natal care centers; (2) the prevention of pre-natal infections (rubella) and post-natal infections (e.g., bacterial meningitis) which involve the central nervous system; (3) enhanced early diagnostic techniques (i.e., amniocentesis) and -- increasingly -- effective treatment in utero of chromosomal and metabolic diseases; (4) the prevention of both external (e.g., lead and mercury) and internal (e.g., Rh incompatibility) intoxication sources; and (5) increasing intervention into the recurring sets of early childhood experiences which so adversely effect developmental potentials (e.g., negative psychosocial learning environments, child abuse, etc.).

Beyond its impact on the incidence of mental retardation, these instances of successful prevention approaches have lifted the previously hopeless cloud

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from these conditions (e.g., "You can't fight the genes...") and have significantly impacted public attitudes and policy (e.g., laws). For example, the past elucidation of the cause of Rh-Factor blood incompatibility has led to a rational approach to its prevention via the use of Rho-GAM to desensitize the Rh (-) mother. Currently, a number of states have the requirement that the Rh type be recorded on marriage licenses registries of known Rh (-) mothers, and programs for the distribution of Rho-GAM.

I envision a marked increase in further prevention efforts at the primary, secondary, and tertiary levels. The impact of these prevention efforts on the reduction of incidence rates now, and increasingly in the future, will strongly influence the number and types of programs (e.g., residential services) and service systems which will be necessary in the future.

In the future we will note a decreased time lag between the generation of new research findings and their direct-indirect translation into programs of help. An interesting current innovation is the recent focus on utilizing the advanced technology of the space program to the creation of micro-mechanical equipment to establish individualized prosthetic environments for severely retarded and multiply handicapped citizens. In the future, we shall see a marked increase in these technological interventions into the developmental history of the severely handicapped individual. In brief, current-future research efforts are focusing on expanding the technological base on which we can devise increasingly more successful preventive and/or treatment intervention approaches.

It should be noted that this current-future focus on prevention and allied early intervention efforts have become national goals in many of the nations of our world: England, France, Sweden, and Denmark. In America, a recent report of the Government Accounting Office ("Preventing Mental Retar-

dation: More Can be Done," Washington, D.C., October 3, 1977) has been enthusiastically endorsed by the President's Committee on Mental Retardation and the National Association for Retarded Citizens. The Carter administration has recently requested specific budget guidelines to implement this challenge.

B. The impact of the ideology of normalization*--and its major corollary, integration of the handicapped--will produce many significant governmental, professional, economic, and public attitudinal changes in our societal postures toward the handicapped. These changes, in my opinion, are in their early phase and will be more clearly manifest in markedly changed patterns of services during the remainder of this century. These future oriented shifts in service delivery include:

- From Professional Monopolies to Shared Leadership. There was a day when certain professions (e.g., medicine) dominated the public care systems for mentally retarded persons. It first gave way to a broader base of leadership in Denmark's statute of 1959, when medical superintendents of institutions were replaced by a four-person directorate (administrator, physician, education and social service director). The consumer advocacy groups are now--and will increasingly in the future--be in a strategically favorable position to use the normalization principle to advocate for a healthy distribution of services carried out by a shared leadership.
- From the Institution as the Mainstay of Service Delivery to a Network of Community-Based Services. For years, industrialized nations tended to segregate and physically isolate mentally retarded persons into remotely located and physically inappropriate units with thousands of residents. The sociological principle by which a system struggles to maintain itself forces many institutions to attack the normalization principle. Yet, we are seeing the current signs of a future trend in the movement from centralized government to decentralized decision making. Normalization, rightly understood, can help a community to solve a handicapped person's needs for growth and support on a local level. Dybwad (1978) noted, "In this battle of shifting empires, centralized government will always feel more comfortable with large, authoritarian institutions than with decentralized, individualized, and dispersed community services." (pg. 39). Accordingly, the current international wave of

* The normalization principle refers specifically to a philosophical position and associated technology for achieving the goal of maximizing culturally acceptable behavior. Retarded individuals should, to the greatest degree possible, be treated as if they were of normal intelligence. This approach focuses on enhancing socially appropriate behavior, a position which is valid on both theoretical and empirical bases. (Nirje, 1969; Menolascino, 1977).

building of comprehensive community systems requires nothing less than an all-out effort on the part of many persons and their governments. Consumer advocacy groups, aided by clear knowledge of the normalization principle have been, and will continue to be, a key force in bringing about this transition.

- From An Exclusive and Academically Oriented School System, to One That is Inclusive and Teaches How to Cope with Life. A major corollary of normalization is the component of integration. Currently, it shows up most vividly in North America public schools--the expression often used is "mainstreaming". Mainstreaming refers to the placement of mentally retarded students with their non-retarded peers in regular public school classes. Access and availability are current issues since the mentally retarded students may have to leave these classes during various portions of the day in order to receive special instruction. This does not necessarily mean, in the future, the end of special classes. Rather, it means that no one should be in a special class who, with assistance, can manage well in a regular class. It will also mean that special classes will be as close to regular classes in location, general programming, and management as the special educational needs of the individual pupil will permit. Normalization has widened the breach between two different types of educators: 1) the educational traditionalist (i.e., elitist) who sees his/her professional responsibility to exclude from education those who he/she deems unworthy, and 2) the educator who welcomes the professional responsibility to maximize all children's potentials, no matter how handicapped or disadvantaged. The mainstreaming thrust will in the very near future, in my opinion, make the educational traditionalist a lost identity.
- From Vocational Rehabilitation to Human Habilitation. Rehabilitation as a structured, governmental activity started as a narrow vocational program for specific groups of "feasible candidates." The Declaration on the Rights of Disabled Persons, adopted by the UN General Assembly in December of 1975--which firmly embodies the normalization principle--has opened the door for the habilitation of all handicapped persons. The Declaration sets forth the habilitation is a right that shall be granted to all disabled persons without any exception whatsoever.

C. Parents of the Retarded -- Their Future Challenges.

Parents of the retarded have now, and will increasingly in the future, demand their retarded son or daughter's rights to receive services -- rather than charity. This current slogan indicates the future passing of the benevolent attitude toward the handicapped. Increasingly, advocates of the retarded have become aware of their children's legal rights, and no longer have to beg for services. Recently, they have utilized their own self-initiated federal court decisions concerning the rights to be free from harm, to receive

adequate treatment, and also they have become aware of their right to access to information about their children. Those who safeguard professional empires know that power is built by refusing to share information, or at least by making it difficult to obtain. In the United States, parents now have the right to inspect their child's school records. This focus on civil rights and allied issues will, in my opinion, dramatically increase in the future.

- A Shift From the "Professional Knows Best" Position to Shared Parent-Professional Decision Making. For years, parents of the handicapped were described as anxiety ridden, over-emotional and unable to take part in educational deliberations that affected the future of their child. With changes being brought about by the normalization principle, the tables are being turned. Today, it is recognized that there is great value in allowing parents to participate fully in decisions involving their own children. The Individual Educational Prescription -- mutually formed by parents and professionals -- in a benchmark of current progress on this vital topic. In the future, it is clear that the handicapped person -- even a child -- will be allowed to decide issues independently insofar as he or she is able.
- From Parental Control to the Recognition of the Handicapped Citizen's Rights. As parents gain more of a voice in decision making, another problem emerges. It follows that there is a limit to parental power if retarded children and adults are to have certain rights of their own. In some cases such rights may conflict with the choices of the parents. There is no precise formula as to when the parents' control should end and the child's rights begin. Currently, questions have been raised about parental power being so unquestioned and absolute that parents can, for example, arrange for the life-time institutionalization of their child, even when his/her quality of living could be remarkably better elsewhere. A current case concerning the rights of parents to institutionalize their retarded children for an indefinite period of time is in the US Supreme Court (Bartley vs. Kremens), and its resolution will have major impact on the future rights of handicapped citizens. I predict that the U.S. Supreme Court will side with the rights of the children -- versus the persistent traditional view that children are the chattel of their parents.

D). Self-Advocacy for Handicapped Citizens.

The Seventies have witnessed an expansion of advocacy approaches, legal and personal advocacy. The former has involved the use of litigation as a means of dealing with such problems as the dehumanizing conditions which have characterized public institutions for the mentally retarded, and the "right to education" suits aimed at opening the doors of public schools to all handi-

capped persons of school age. A prime example of personal advocacy is the Citizen Advocacy Model. (NARC, 1977).

In the future, we will increasingly see an even more exciting thrust; self-advocacy by handicapped individuals themselves. This approach has been utilized in a few isolated instances, including: People First, and organization founded by and for mentally retarded persons; The Milwaukee Citizen, a newspaper published by mentally retarded adults for their peers; and Polling Magazine, a publication edited by an individual with cerebral palsy for the purpose of providing a forum to highlight their concerns and problems.

In the future, self-representation and self-advocacy by mentally retarded and other developmentally disabled individuals will have virtually limitless potential for assisting this handicapped segment of our society to exercise their rights as citizens, including more direct access to needed services. Its full implementation will, however, require sophisticated training materials and consultation capabilities to prepare developmentally handicapped persons to assume an active role in safeguarding their rights.

E. Increasing Consumer Advocate Capabilities for Catalyzing and Monitoring Community Services for Mentally Retarded and Other Developmentally Disabled Persons.

At present, large numbers of mentally retarded individuals are being discharged from institutions and returned to the community. Considerable evidence is already available which indicates that many of these persons are being exploited or neglected because of inadequate community resources. The entire deinstitutionalization thrust may thus be in serious jeopardy unless a mutual community integration thrust of quality services are simultaneously developed.

Throughout the world, there is considerable variation in the degree to which communities are providing coordinated service systems aimed at meeting the lifelong needs of handicapped citizens. In some cases, the programs

which have evolved are poorly planned and of questionable quality. In other instances, responsible government agencies have made only token gestures to develop meaningful programs.

Ensuring the availability of appropriate services will require an informed and active corps of consumer advocates equipped to press for the development of needed services, closely monitor existing programs and, where necessary, take the initiative in ensuring that positive changes are undertaken. For example, the National Association for Retarded Citizens has already demonstrated the feasibility of such an approach by producing and distributing a series of detailed materials and related training packages designed to increase the expertise of parents and other consumer representatives in evaluating and upgrading institutional services. In the future there is a pressing need for a complementary set of materials dealing with community-based services.

F. Home Training for Severly Handicapped Citizens: Future Trends

The potential contribution that parents can make as teacher, of their handicapped children, both in the home during the early years of life and, later, as a supplement to school-based and adult service programs cannot be minimized. It has been recognized that meaningful education must be fully articulated with the real world, and cannot remain isolated from the home, family, and the community in which handicapped citizens spend the major portion of their lives. The need for more relevant educational activities is currently most acute in the case of severely and profoundly mentally retarded individuals. Clearly, there is a need for a life-long continuing commitment to teaching those individuals an ever increasing repertoire of life skills. Though expensive during the early developmental years, the long term payoff--both economically and humanistically--are very appreciable for both these significantly handicapped individuals and their society.

The successful implementation of behavioral techniques in the home environment has received considerable attention since the mid-1960's. We are recognizing the major importance of parents as key participants in the education and training of their children. The current "state of the art" reveals that, increasingly, home training materials have become available to interested parents. A number of parent teaching programs and teaching aids are available either commercially or from a variety of research projects. These programs cover the specifics of self-care skills, social behavior, language, motor skills and basic academic readiness work.

Despite the encouraging progress that has been made in evolving home training programs, there continues to be a marked need for future home training materials which will meet a wide range of parental needs. For example, it is not sufficient to develop procedures which only apply to middle socioeconomic families in an urban locale, or parents who are willing and able to give full cooperation to the program. Future efforts must be made to encompass parents with differing social, economic, and ethnic backgrounds, single parents, and those who are only passively interested. One future way to achieve personalized home training instruction would be to incorporate procedures that enable trained parents to tutor and supervise other parents with in-home training activities. In the future, I believe that we shall see a marked increase in this model of the trained parent being utilized as an effective tutor-supervisor-advocate.

G. Increased Focus on Curative Approaches to the Mentally Retarded.

The word "cure" so often smacks of quackery when applied to significantly handicapped citizens such as the severely retarded. A number of epistemological questions are quickly brought forth, the emitter is tactfully asked if he has confused the word with the concept of prevention, and direct statements are made about unduly raising the hopes of parents of the currently retarded--

let alone their future mirror images! Yet, we have made many significant gains in curative approaches. Today we can state that contemporary approaches to the treatment and management of the mentally retarded encompass the following approaches to the primary, secondary, and the tertiary prevention challenges which are present:

- A. Cure for a few - e.g., Murphy's disease, PKU, hypothyroidism, craniostenosis, etc.
- B. Treatment for many - e.g., control of seizures, visual and auditory services, motor prostheses, psychotherapy and psychoactive pharmacological agents for managing allied emotional-personality problems, etc.
- C. Habilitation for all - maximizing intellectual, social-adaptive and vocational potentials via specific educational, social-recreational, vocational and residential programs.

Further, we have for some time now been very effective in obtaining "partial" cures--the alleviation, minimization and/or control of many of the frequent accompanying symptoms which hinder the retarded citizen's ultimate developmental progress. In other words, the alleviation of secondary symptoms (e.g., effective seizure management), has served to minimize the level of the handicap. For example, some of our mildly retarded citizens have, with special help, been able to function in the non-retarded range.

Currently, there is a burgeoning amount of basic-applied research efforts which promise realistic payoffs in the very near future. Included in these future approaches to cure are: (1) recent work which shows that the enzyme errors in some of the inborn errors of metabolism can be reversed by cultured and implanted skin fragments (e.g., fibroblasts in glycoprotein disorders); (2) current animal research which clearly illustrates that neuronal regeneration in the spinal column and brain is possible; (3) continuing research on an increasing number of psychopharmacological agents with memory and/

or learning enhancement characteristics; (4) recent attempts to reduce the RNA turnover rate in "extra" chromosome disorders such as Down's Syndrome; and (5) utilizing amniocentesis to confirm pre-natal signs of neural tube defects, and--rather than recommend abortion as a "treatment"--utilize intra-uterine surgery on the fetus to correct lesions such as a meningomyelocele.

Rather than get lost in the swirling debates as to what is "cure"--it seems clear that the future will increasingly see the utilization of very early fetus-infant-child interventive techniques to cure the "incurable".

H. Lastly, the Community Will Increasingly Make Their Service Provision Decisions On the Basis of Cost-Service Benefit Considerations. Today, it is more common to belittle cost evaluations and they often tend to occur as an afterthought. In the future, we will see ongoing program cost(s) evaluation budgeted in "up front", close monitoring of service delivery, and discrete cost-service benefit studies as an integral part of all budgetary considerations in programs for the handicapped. Further, I predict that rather than the "hardnose bottom line" mentality of business enterprises, we shall see the criteria for cost containment based upon variables which fully embrace the humanistic dimensions of what handicapped persons, in which programs, and for how long--best fulfills their individual needs. This cost-service benefit approach will eventuate, in my opinion, in a renewed focus on the conservation and maximization of human resources as very worthy of our societal-professional time, efforts, and financial resources.

SUMMARY

I believe that the future will be more people-oriented--along the lines of the eight future trends which I have only briefly reviewed. Further I believe that the future of the handicapped citizen in his community--across our world--will encompass the full impacts of today's key

ideologies in human service, the fruits of research and prevention efforts, a continuing quest to bring equal rights to a group of citizens who have for too long been termed "unequal", and a persisting strong advocacy group of parents, professionals, and handicapped citizens themselves who will keep pushing back the future horizons of help and hope.

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